

Reducing Perinatal Transmission: The Role of the National Organizations

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Pediatricians' Role in Preventing Perinatal HIV Transmission: American Academy of Pediatrics Project Update

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The American Academy of Pediatrics (AAP) is a not-for-profit professional membership organization committed to the attainment of optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults. Founded in 1930 by 35 pediatricians, the AAP now has a membership of approximately 55,000 pediatricians. Current AAP goals focus on developing policy and programs in five specific areas: advocacy, education, research, service, and improving the systems through which pediatric care is delivered.

The AAP believes that pediatricians play an essential role in the further reduction of perinatal HIV transmission. Through its Committee on Pediatric AIDS, the Academy has issued several policy statements to its members covering such topics as perinatal HIV infection and testing, HIV transmission through breast-feeding, education of children with HIV, and evaluation and medical treatment of the HIV-exposed infant. All policy statements are available on the Academy website (<http://www.aap.org>).

The primary goal of this project is to address further reduction in the rate of perinatal HIV transmission through the education of pediatricians and through collaborative work with other professional organizations.

Project objectives include:

- educating AAP members about the importance of the 1999 Institute of Medicine (IOM) report, *Reducing the Odds*, and the 1999 AAP/American College of Obstetricians and Gynecologists (ACOG) joint statement, "Human Immunodeficiency Virus Screening;"
- evaluating the knowledge, attitudes and behaviors of AAP members pertaining to the issue of HIV screening as a tool for the further reduction of perinatal HIV transmission; and
- working collaboratively with health care organizations to discuss quality assurance measures as a tool for changing physician behaviors.

Several activities have been undertaken to further educate AAP members about the importance of universal HIV testing, with patient notification, as a routine standard of care. In April 2000, the Academy disseminated educational materials to its 55,000 members through a batch mailing. The following components were included as a special “Perinatal HIV Prevention” insert:

- a cover letter from the AAP president highlighting the importance of pediatrician involvement in this issue;
- three patient education brochures: “Know the Facts About HIV and AIDS,” and “What Every Woman Should Know About HIV and AIDS (English and Spanish),” developed by the AAP and the Elizabeth Glaser Pediatric AIDS Foundation (PAF), respectively;
- an accompanying poster from the PAF entitled “Which Woman Should Get an HIV Test?”; and
- a “fact sheet” which briefly summarized perinatal HIV transmission issues.

In April 2000 the AAP reprinted the Executive Summary from the IOM Report, “*Reducing the Odds: Preventing Perinatal Transmission of HIV in the United States*,” in their news magazine, *AAP News*. The IOM report recommended “the adoption of a national policy of universal HIV testing, with patient notification, as a routine component of prenatal care.”

In May 2000, the AAP Department of Pediatric Research began plans to conduct a Periodic Survey of Fellows to evaluate the knowledge, attitudes, and behaviors of AAP members pertaining to further reduction of perinatal HIV transmission. Data collection is planned for spring 2001. The survey will be mailed to 1,600 Academy Fellows; a response rate of 70% is typically achieved. The Committee will carefully review the results and suggest mechanisms for how the AAP can continue to educate its membership on this topic in an effort to effect behavior change. The results will be published in a peer-reviewed publication.

Preliminary communications have begun with the American Hospital Association (AHA) and the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) to make the offering of HIV testing to pregnant women an assessment parameter for quality assurance. We would like to think optimistically that we could arrange further discussions with our colleagues to have this incorporated as an essential standard of care. It is hoped that if this measure reflects quality assurance, not only will physicians be educated, but also a change in behavior (i.e., physician practices) will be achieved.

Materials Available

- AAP *Fact Sheet* on perinatal HIV transmission
- AAP Committee on Pediatric AIDS policy statement / technical report listing
- AAP Patient education brochure, *Know the Facts About HIV and AIDS*
- Joint statement of ACOG/AAP on HIV Screening
- *What Every Woman Should Know About HIV and AIDS* (brochure from PAF)
- *Which Woman Should Get an HIV Test?* (poster from PAF)

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HIV Infection and Pregnancy: Managing Mother and Baby

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National Pediatric & Family HIV Resource Center

The goals of the National Pediatric & Family HIV Resource Center (NPHRC) project are to: a) increase providers' knowledge about HIV counseling and testing of pregnant women; and b) increase providers' understanding of strategies to reduce perinatal HIV transmission. Using the train-the-trainer model, we will target four jurisdictions over 2 years.

Methodology

NPHRC partners with key state organizations who are asked to assist with publicity, help identify and recruit providers to be trainers, co-sponsor the faculty training, and assist in scheduling speaking engagements. We selected the train-the-trainer model because it a) builds on the expertise of practicing clinicians; b) is an effective way to educate large numbers of providers; and c) leaves ongoing expertise in the community.

The goal of the training is to increase women's health care providers' knowledge of and skill in:

- HIV counseling and testing in pregnancy
- medical management of HIV in pregnancy
- strategies for the reduction of perinatal HIV transmission
- controversies in perinatal HIV care (e.g., cesarean sections)
- adult learning strategies.

An advisory group, consisting of a broad spectrum of reviewers, assisted in planning for the faculty training. NPHRC developed a slide set and speaker notes that all trainers will use; a consultant (an obstetrician) provided content expertise at this phase. We also developed supporting materials: articles and a list of references; provider and consumer materials; and a region-specific "pocket card" that contains an overview of perinatal HIV management and provider guidelines. An important part of the training is the discussion and modeling of educational strategies that have proven to be effective for adult learners.

To make it easy for busy clinicians to do training, the local AETC can arrange for the marketing and logistics required for each session. Trainer packets will contain all the materials they need and key organizations will be engaged as local facilitators. Speakers will be paid. We will also set up a Listserv so that we can update references as necessary.

Initial Target Areas: Mississippi and Washington, D.C.

In Mississippi we have been working with the Delta AIDS Education and Training Center (AETC), the University of Mississippi HIV Resource Center, and the March of Dimes. In Washington, D.C., we have been working with the National Minority AETC and the Administration for HIV/AIDS of the D.C. Department of Health.

In Mississippi in August 2000, we held a total of five faculty workshops in 4 major cities to introduce the train-the-trainer program. There were 64 participants. Sixteen of these have agreed to be trainers: 5 registered nurses, 4 nurse practitioners, 3 M.D.'s, 2 certified nurse midwives, and 2 social workers. Our trainers have already begun in the field.

Two faculty workshops in Washington, D.C. (August 2000 and January 2001) attracted 61 participants; many were fairly high-level providers. Twenty-one have agreed to be trainers: 10 nurses, 3 M.D.'s, 3 certified nurse midwives, 3 social workers, one physician's assistant, and one "other."

There have been expected and unexpected outcomes from our first forays into the field. In Mississippi, networks were built; providers (obstetricians and pediatricians) in rural areas who would provide care for HIV-infected pregnant women and infants (so that they would not have far to travel) were identified; and "local experts" were identified. The Washington, D.C. workshops revealed the need for basic training programs in preventing perinatal HIV transmission. We had to turn people away from the faculty training workshops by assuring them that trainers would eventually come to them. Here too, there was the identification and recognition of local experts.

Lessons Learned

An initial evaluation of the workshops in the two areas revealed:

- the training process and materials were effective (especially if participants were fed!)
- knowledge gains on the part of trainers were documented by pre- and post-workshop tests
- some differences between states in baseline trainer knowledge, but
- no significant differences between states in knowledge gain.

We learned several other lessons:

1. In addition to input from the local advisory committees, we needed to use our own expertise in identifying speakers for the workshop.
2. We needed to let potential trainers know that they would be using standardized content and slides when they went into the field. Also needed to ensure appropriate and willing participants for the workshop (train-the-trainer workshop vs. general workshop).
3. A large state will need multiple workshops.
4. The faculty training workshop takes a minimum of 4 hours (including instruction on how to teach others).
5. We needed to empower the sites to take over and go to the next step.
6. Experts have training needs too. Local clinical experts demonstrated an increase in knowledge from baseline, in both high- and low-incidence regions.
7. A standardized curriculum is important. It promotes consistent knowledge gain in participants despite diverse faculty.

What's Next?

The next geographical areas we will focus on are central Florida and Tennessee/Alabama. Thus far we have created a steering committee for Florida and made contact with key players in Tennessee/Alabama.

We are updating slides and references and communicating changes in the science to our trainers. We intend to provide follow-up support for training done by our trainers and also do a 6-month follow-up of trainees, that is, those trained by our trainers. We will use a pre-test, post-test evaluation instrument.

The Association of Maternal and Child Health Programs: Reducing Perinatal HIV Transmission Through Assessment, Policy Development and Assurance

Nancy Maddox, Maren Enterprises, Inc.

Carol Watson, Association of Maternal & Child Health Programs

The Association of Maternal & Child Health Programs (AMCHP) is a national non-profit organization made up principally of the directors and staff of state public health agency programs for maternal and child health and children with special health care needs. On October 1, 1999, AMCHP entered into a 3-year cooperative agreement with the CDC's National Center for HIV, STD and TB Prevention to help achieve national objectives related to perinatal HIV transmission and pediatric AIDS. Through this cooperative agreement, the Association aims to build and strengthen Title V program capacity to carry out three broad public health activities: assessment of the prevalence and incidence of HIV infection among infants and reproductive-age women; development of policies to prevent perinatal HIV transmission; and assurance that high-quality HIV screening and treatment services are available and accessible to all women within states. As part of this cooperative agreement, AMCHP will be involved in the following three activities:

- **Development of a Perinatal HIV Policy Manual**

AMCHP is convening an expert panel to develop a perinatal HIV Policy Manual. The goal of the perinatal HIV Policy Manual is to encourage and assist states to broaden and refine the scope of their activities to prevent perinatal HIV transmission. [See Appendix A for more information.]

- **Planning and Implementation of Multi-State Action Learning Labs**

AMCHP will bring together cross-program teams of state health officials and other key players involved in the prevention of HIV transmission from pregnant women to their infants. The Action Learning Labs (ALL) will present an important opportunity for states to review current HIV prevention policies in a comprehensive fashion and to identify systems changes that will not only strengthen perinatal HIV prevention activities, but other state health efforts as well. [See Appendix B for more information.]

- **Technical Assistance to States, Information Dissemination, and Other Activities**

AMCHP will continue to provide technical assistance to states. Examples of technical assistance include the following:

- Technical assistance to states' to strengthen HIV surveillance capabilities and help them better determine the number of pregnant women being tested for HIV, as well as those missed;
- Policy analyses and dissemination of information via issue briefs and other reports, AMCHP's Updates newsletter, conference calls, workshops, conferences and AMCHP's website (www.amchp.org);

- Development of internet-based services to link professionals with training/educational materials for providers and consumers; and
- Facilitation of the development of performance measures related to perinatal HIV transmission.

Related Products

Report: *Playing It Safe: A Survey of MCH Activities to Stop the Spread of Perinatal AIDS*

Position Paper: *HIV Counseling and Testing for Pregnant Women*

Appendix A

Perinatal HIV Policy Manual Overview Draft February 2001

Background

The HIV ‘policy manual’ or ‘tool kit’ is envisioned as one way to encourage and assist states—and state MCH programs, in particular—to broaden and refine the scope of their activities to prevent perinatal HIV transmission. The manual will present an array of options states might consider in a plethora of programmatic areas (as well as likely outcomes from various policy options, to the extent known). It will also provide reliable sources for materials and further information related to the topics discussed. (In some cases, materials, such as sample HIV-test consent forms, may be included in the manual.) And finally, it will attempt to address common challenges states face as they devise and implement policy, assessment, and assurance activities that impact very personal human behaviors in potentially very different demographic and policy environments. In short, a one-stop-shopping manual for decision-makers concerned about perinatal HIV transmission. The manual will be developed under the auspices of the Association of Maternal & Child Health Programs’ cooperative agreement with CDC’s National Center for HIV, STD, and TB Prevention.

Possible Content Areas

- *Models for integration of MCH and HIV program activities*

This section would showcase examples of successful collaboration that runs the gamut from very formal (e.g., involving official memoranda-of-understanding and/or other contractual relationships) to very informal (e.g., unofficial cross-program workgroups). It would address integration of HIV activities in established programs (e.g., family planning, WIC, pediatric care, abstinence education, school health, CSHCN, etc.) at each point along the continuum of care, and would highlight the MCH model of family-centered, community-based, and culturally competent care. (Integration would also be touched upon, as appropriate, in each of the areas that follow.)

- *Consumer involvement in state HIV policy-making and oversight*

Would provide examples of consumer involvement in the full range of activities discussed in the manual. (Alternately, consumer involvement could be addressed separately in each content area.)

- *Surveillance and data collection*

Would provide information on data collection protocols and other promising assessment options to help states determine a) what proportion of pregnant women are being screened for HIV, and b) who is systematically being missed. Ideally, examples would encompass case-control or retrospective studies (involving chart reviews of HIV-positive infants, HIV-positive women who have given birth and/or women who received no prenatal care), and determination of seroprevalence among women with no known risk factors and/or among women who have tested negative for HIV.

Would help states deal with common data collection challenges, such as the difficulty of assessing who is being tested when testing is anonymous and the barrier posed by HIV confidentiality laws that preclude questions about prenatal HIV testing on well-established surveys like PRAMS.

Would address quality assurance issues, including performance measures.

Would possibly discuss surveillance of children exposed to zidovudine prenatally.

- *Outreach*

Would provide examples of successful outreach to the general public and to specific groups, possibly including youth, minority women, women who are prepartum or interpartum, rural women, homeless women, non-English speakers, substance-abusers, incarcerated women, undocumented aliens, the uninsured, etc. Social marketing would be incorporated as one form of outreach.

- *Case Management*

Would address the experience of individuals within the health system, including coordination of health services, delivery of enabling services (e.g., transportation and translation services), patient advocacy, etc.

- *Counseling and Testing Policies*

Would discuss the relative merits and success of different state counseling and testing policies, including mandatory testing for pregnant women, consent options (and sample consent forms), the role of rapid testing, and various pre-test counseling options.

Note: The manual will not address detailed clinical protocols, but may provide references to established sources of clinical information.

- *Provider Training*

Would provide examples of successful provider training activities, as well as sample training materials for health professionals and sample educational materials for consumers, or information on how to obtain them. (Would especially attempt to identify consumer materials regarding rapid testing.) Would discuss barriers that keep some providers from testing all prenatal patients.

- *Funding*

Would discuss options to fund enhanced HIV counseling for women and other HIV activities (e.g., Medicaid enhanced psychosocial and nutritional services, agreements with third party payers, family planning waivers to increase service delivery to women up to 200% of FPL, etc.). (Alternately, funding may be discussed as a subsection of each of the above topics.)

Appendix B

Association of Maternal and Child Health Programs Perinatal HIV Action Learning Labs

The Problem

The success of the drug zidovudine (ZDV) in reducing the rate of transmission of the human immunodeficiency virus (HIV) from an infected mother to her newborn infant was hailed as "one of the most promising victories in the battle against AIDS (acquired immunodeficiency syndrome)."¹ Since the drug made its public debut, the incidence of pediatric AIDS in the US has plummeted.^{2,3,4} Better counseling and testing practices have also contributed to the decrease in the progression of AIDS. Between the peak of the epidemic in 1992 and 1998, the estimated number of new cases fell by 75%.⁵

Yet, the Centers for Disease Control and Prevention estimates that 300 to 400 babies are still born with HIV infection every year in the United States.⁶ In short, the nation has yet to capitalize on the best that modern medicine has to offer for all American women and their children.

In its 1998 report, *Reducing the Odds: Preventing Perinatal Transmission of HIV in the United States*, the Institute of Medicine found that despite substantial improvements in provider practices and a large reduction in the number of perinatal AIDS cases, "so much more remains to be done."¹ Even though Public Health Service guidelines on prenatal HIV counseling, testing, and treatment have been implemented in diverse ways across the country, no one approach was found to be superior. Pregnant women are generally receptive to HIV testing and ZDV therapy, if necessary, but too few women are tested.

The IOM Committee on Perinatal Transmission of HIV concluded that the "most effective change" would be to increase the number of pregnant women who are offered and accept HIV testing by prenatal care providers. The Committee also determined that a comprehensive approach to prevent perinatal HIV transmission must include many complex elements; elements that state and local health systems are still struggling to implement and refine:

- Strategies to prevent women from becoming infected with HIV
- Efforts to increase the utilization of preconception and prenatal care by all women who are pregnant or considering childbearing
- Efforts to address women's concerns about HIV testing and treatment
- Continuing education for prenatal care providers and other activities to improve provider practices (e.g., the use of performance measures)
- Improved quality and coordination of prenatal and postpartum primary care for all women, including those with HIV infection
- Improved counseling for at risk women and those living with HIV
- Better access to high-quality HIV treatments and support services for infected women
- Efforts to avert unintended pregnancy and childbearing among all women, including those with HIV infection
- Continued disease surveillance to help evaluate and refine programs and policies intended to prevent the spread of HIV/AIDS.

Proposed Solution: Action Learning Lab (ALL)

The Association of Maternal and Child Health Programs (AMCHP), through a cooperative agreement with the Centers for Disease Control and Prevention, Center for HIV, STD, and TB Prevention is sponsoring a two-part Action Learning Lab (ALL) to bring together cross-program teams of state health officials and other key players involved in the prevention of HIV transmission from pregnant women to their infants. AMCHP is collaborating with the American College of Obstetricians and Gynecologists (ACOG), the Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau, and CityMatCH. AMCHP has also received input from the National Association of State and Territorial AIDS Directors.

AMCHP and ACOG bring considerable expertise to this undertaking, both in terms of the substantive issues which will be the focus of the Learning Labs and the ability to organize such an activity.

Overview

The first Learning Lab will take place in Washington, D.C., and will guide participants through a structured, hands-on process to

- Catalog state assets that facilitate prevention of perinatal HIV transmission;
- Catalog barriers that hinder the prevention of perinatal HIV transmission;
- Determine ways to integrate the work of key players (including health officials supported by the Title V, Title IV, Title II, ACOG chapters, AIDS Education and Training Centers, the American Academy of Pediatrics and Title X programs) to reduce duplicative efforts and to achieve the best client outcomes and experience within the health system;
- Problem-solve with recognized experts in relevant fields (e.g., data collection, provider training, and other areas identified by participants); and
- Develop a six-month action plan to institute short-term systems changes.

Participants will come away from the first Learning Lab with a good idea of what's working within their state, a feeling for how well it's working, and a plan for sustainable actions to improve it. They will re-convene about six months later for a follow-up Learning Lab to assess short-term progress, continue problem-solving, and formulate longer-range goals.

Hallmarks of the Learning Lab experience are

- an informal, interactive format for most activities;
- presentation of timely, real-world information by participants from several states and by outside experts, all of whom are acquainted with the issues at-hand; and
- the opportunity to build relationships with and learn from key policy-makers from participants' own and other states.

Learning Labs are structured to accommodate several participants from each state, who collectively form a traveling state team. Ideally, each traveling team member will represent a larger group of individuals

within the state (e.g., select individuals whom they supervise, the executive leadership of a non-profit organization, etc.). Together, these non-traveling individuals comprise the “home team.” Both traveling and home team members should be key stakeholders who oversee or can otherwise influence processes that impact perinatal HIV transmission. After each on-site Learning Lab, home teams should be debriefed and involved in action steps, as appropriate.

Learning Labs work best when participants are committed

- to work together across program boundaries and turfs;
- to leverage resources in the face of political and financial constraints;
- to undertake sustained activities that will lead to beneficial systems changes; and
- to participate in all Learning Lab activities.

Overall, AMCHP provides funding to cover travel expenses for up to five individuals per state, provides conference materials and meeting facilitation, and arranges for health experts to be available for on-site technical assistance. AMCHP may also arrange follow-up technical assistance, as requested by state teams after the first Learning Lab. ACOG will provide funding and appropriate technical assistance so that one private sector obstetrician/gynecologist can be part of the traveling team from each participating state.

Eligibility

For the first installation of Action Learning Labs on this topic, AMCHP and ACOG are targeting states with the highest rates of perinatal HIV transmission and states with worsening or unchanging transmission rates, as reported by the CDC. Each of these states is eligible to submit one application.

Team Composition

AMCHP will pay for the participation of five traveling team members per state. ACOG will pay for the participation of one traveling private sector ob/gyn per state. States are free to add additional traveling members at their own expense. Traveling teams must include at least one private sector ob/gyn and at least one representative from the state Title V program (MCH or CSHCN), Title IV program (if extant), Title II program (if extant), and Title X program. Additional traveling members may be chosen at state discretion, possibly including managed care officials, Medicaid, and/or other state officials, etc.

Consumer involvement in traveling and/or home teams is strongly **encouraged**. Home teams may be composed at state discretion, with no size limitation. Regardless of team size, all members (in both traveling and home teams) must have sufficient authority/influence to effect systems changes within the state.

Selection Criteria

Applicants will be selected based on their ability to demonstrate that they a) can bring together appropriate traveling and home teams; b) have realistic learning goals and expectations; c) are committed to participating in all required activities (including the screening conference call; both on-site meetings, any agreed-upon follow-up activities, and an ALL evaluation); d) are committed to effect

changes within the health system; and e) have capacity to effect change. A total of 7 state teams will be selected to participate.

Timeline

Deadline for receipt of e-mail indicating intent to submit an application	April 27, 2001
Deadline for receipt of applications	May 25, 2001
Screening Conference Calls	Will take place on June 4, 7, 8, 11, and 12
Applicants Notified of Selection Status	The week of June 18
First ALL	July 25 and 26, 2001
Second ALL	January or February 2002 (Date to be determined)

Inquiries

Address applications, e-mail notifications, and general inquiries regarding the program to

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Address any inquiries regarding selection of a private sector obstetrician/ gynecologist to participate in traveling teams to

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¹IOM. *Reducing the odds. Preventing perinatal transmission of HIV in the United States*. Washington, DC: National Academy Press, 1998.

²CDC. Update: perinatally acquired HIV/AIDS-United States, 1997. *MMWR*. 1997;46:1086-92.

³Cooper ER, Nugent RP, Diaz C, et al. After AIDS clinical trial 076: The changing pattern of zidovudine use during pregnancy, and the subsequent reduction in the vertical transmission of human immunodeficiency virus in a cohort of infected women and their infants. *J Infect Dis*. 1996;174:1207.

⁴Lindgren ML, Byers RH, Thomas P, et al. Trends in perinatal HIV/AIDS in the United States. *JAMA*. 1999;282:531-8.

⁵CDC. *HIV/AIDS Surveillance Report, Year end 1998*. 1999;10(2).

⁶CDC. *HIV/AIDS Surveillance Report, Year end 1999*. 2000;11(2)

2001 Update: Preventing Perinatal Transmission of HIV in U.S. Cities: An ATPM Cooperative Agreement between CityMatCH at University of Nebraska Medical Center and CDC's National Center for HIV, STD and TB Prevention

Deanna Bartee

CityMatCH at the University of Nebraska Medical Center

The mission of CityMatCH is: improving the health and well-being of urban women, children and families by strengthening the public health organizations and leaders in their communities. It offers:

- a responsive, active network of urban health departments serving cities with populations over 100,000
- urban public health data and research (epidemiology, health services, policy)
- proven products and services:
 - CityLights quarterly newsletter
 - NewsBriefs--biweekly E-mail updates
 - *Lessons Learned*--model programs and initiatives
 - Urban MCH Data Use Institute
 - Urban MCH Leadership Conference
 - Urban MCH Learning Clusters.

Pediatrics AIDS is an overwhelmingly urban phenomenon: 85% of cases are in the 100 largest metro areas, and 73% of cases are in 29 of the larger metro areas. Thus, an urban focus for prevention of perinatal HIV transmission is critical.

The CDC-CityMatCH partnership focuses on promoting the translation of research and data into effective practice in U.S. urban communities with the highest rates of perinatal HIV. The goals for this project are:

- to inform and engage urban health departments and leaders in the prevention of perinatal transmission of HIV/AIDS; and
- to promote learning across urban communities with the highest concentrations of perinatal HIV transmission
 - to identify and promote more effective, sustainable approaches to assessment and prevention; and
 - to achieve measurable results in HIV prevention.

To date, several activities have contributed to progress in achieving the first goal. A special edition (September 2000) of *CityLights*, our quarterly newsletter, focused on this issue. We developed pages on "Learning Clusters" for our website, www.CityMatCH.org. A display and other activities were devoted to perinatal HIV prevention at the 2000 CityMatCH conference and this topic will be the focus of our 2001 conference.

To achieve goal 2, we will be using what we call “Learning Clusters” to identify urban-specific prevention strategies and to promote exchange of ideas and technical assistance among peers. Learning Clusters can be defined by the following characteristics:

- strategically composed group of individuals and teams brought together for both “giving and getting”
- focuses on a public health issue or methodology of shared interest
- combines science, program and policy experts and community-based teams
- defines and yields mutually useful products and information.

The teams brought together from different cities are the core of the Learning Cluster. Subject-matter expertise, such as that provided by CDC, and other resources (e.g., a local person who can provide a consumer perspective) are also brought into the mix. City team members represent: HIV program/policy expertise, MCH program/policy expertise, public health leadership, community leadership, state representation, and clinical liaison.

There are several assumptions behind the Learning Clusters approach. First, there are prevention methods or interventions that are promising or have proven successful in urban settings, but are not fully in use. Second, communities with a high interest and need for such methods or interventions are not currently connected. Third, in some cases, current activities within a community are not optimally connected. Finally, local health departments can provide core leadership for community synergy.

The role of City**MatCH** is to host these Cluster meetings and to fund the participation of some members of the teams from various cities. It also sends out bi-weekly e-mails on communication for collaboration, and arranges for information dissemination from an expert source through Cluster learning calls. It also brokers the “give and get” of the Learning Clusters. The role of the city teams is to develop a city-specific action plan, develop cross-Cluster initiatives, and to exchange ideas and technical assistance among peers.

Five urban Learning Cluster teams were enrolled in 2000: Los Angeles, California; Miami, Florida; Norfolk, Virginia; Philadelphia, Pennsylvania; and Washington, D.C. Our first Perinatal HIV Urban Learning Cluster Meeting was held in Atlanta, Georgia on April 17 -18, 2000. Participants were afforded the following opportunities:

- understanding the Urban Learning Cluster approach
- getting to know your team
- common framework for preventing perinatal HIV transmission
- sharing knowledge base for preventing perinatal HIV transmission through panel discussion
- identifying Opportunities for Impact (OFI) within and across cities
- team planning.

The second Perinatal HIV Urban Learning Cluster Meeting, in Miami, Florida, December 8-9, 2000 provided the following opportunities:

- five exciting and informative site visits
- cross-team collaboration

- learning around program evaluation
- team planning.

Four areas of cross-team collaboration were highlighted at this meeting: social marketing, MCH/HIV integration, surveillance, and standards of care. The Miami site visits produced several “pearls” as participants observed:

- continued opportunity for purposeful education;
- consistent and constant community outreach efforts targeted to high-risk communities to establish and build “trust” with youth at risk; and
- excellent parenting education models for teaching self-reliance and empowerment.

We have already begun the process of adding new cities to the Learning Cluster in 2001. Activities this year will include the Third Perinatal HIV Urban Learning Cluster Meeting in Philadelphia April 1-3, 2001 (with the 2000 Urban Learning Cluster Action Teams). We will invite 3-5 potential 2001 Urban Learning Cluster Action Team’s identified MCH and HIV co-leads to meet with us and then select 2-3 Action Teams to add to the current Perinatal HIV Urban Learning Cluster. Our hope at City**MatCH** is to use the three years of the grant to get the Learning Clusters started and then to turn the project over to the cities themselves so they can continue to help each other.

CityMatCH Project Team

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Kelly McIntosh - *Staff Secretary*

AIDS Alliance for Children, Youth & Families

David Harvey

AIDS Alliance for Children, Youth & Families

The AIDS Alliance for Children, Youth & Families is an organization that spun off of the National Pediatric and Family HIV Resource Center in 1994. We were started in response to the Ryan White Title IV programs, which focus exclusively on the needs of women, children, and families affected by HIV. Title IV has grown a lot in the last few years, particularly around the issues of adolescents. It contracts with 66 lead programs that in turn subcontract with about 550 clinical sites in 31 states; these sites are actually doing the work of reducing perinatal transmission. So it is a very good infrastructure for reaching providers out there who are doing this work on a daily basis.

A Ford Foundation Grant in 1998 enabled us to do policy research around counseling and testing issues and led to two publications: “Understanding the Debate: Pregnant Women and HIV Counseling and Testing” and “Pregnant Women and HIV Counseling and Testing: Recommendations.” So our organization has a long history of working on policy and legislative issues. We also conduct education and training activities.

Currently we have a consumer education training center based on the train-the-trainer model where we’re working with families, women, and young people from around the country. These “trainers” then go back into the community and do outreach education to other people living with HIV with the goal being to get them into the health care system. This project is going to require a very complicated evaluation strategy to assess what the trainers learned and took back into the community, who they were able to reach and what were the outcomes.

All of this is background for the project that we will be doing with the CDC. There will be five major activities:

- working with CDC to develop a needs assessment of Title IV grantees (needs or gaps at the local provider level) so that information can be funneled back both to AIDS Alliance and CDC. Title IV allows funding directly for both prevention and care (very important when we’re talking about reducing perinatal transmission);
- e-mail alerts (in the past used to get the word out on topics such as the draft CDC guidelines on counseling and testing) to providers and other organizations on our ListServ, which currently numbers about 1200 subscribers. This vehicle will be used repeatedly in relation to this project;
- update programs with current information on policy issues (e.g., provisions of new Ryan White Care Act Amendments, implications of policy on clinical issues) through revision of our booklet, “Understanding the Debate: Pregnant Women and HIV Counseling and Testing;”
- Voices 2001, our annual conference will have a track on perinatal HIV prevention (the conference draws most of the Title IV programs in addition to the research community); and
- add a new module to our consumer train-the-trainer program specifically on the issues of preventing perinatal transmission, especially around counseling and testing.